

Cyflwynwyd yr ymateb hwn i'r [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar gyfer yr ymchwiliad: [A oes gan blant a phobl ifanc anabl fynediad cyfartal at addysg a gofal plant?](#)

This response was submitted to the [Children, Young People and Education Committee](#) for the inquiry: [Do disabled children and young people have equal access to education and childcare?](#)

AEC 66

Ymateb gan: [Joining the Dots Parent Carers](#)

Response from: [Joining the Dots Parent Carers](#)

We are an online group made up of parent carers who live in Wales. The group provides peer support and signposting for each other in things that matter to us and for our disabled children, young people and adults – and we learn from each other along the way.

The group has been running for over 8 years and has over 1000 members.

Our response to this inquiry is compiled from parent carer responses to each question. Many parent carers do not have the time to personally respond to the inquiry so this response gives them a voice. It is very down to earth and real!

Do disabled children and young people have equal access to education and childcare?

- . No! My child went to a unit in mainstream until 11, then a special school till they were 16 they were not ready for college, unfortunately our area only provides school education up to 18 in faith schools, Welsh schools or 1 severely disabled school. I think this is discrimination. Many of their classmates would have preferred to stay in their special school until 18. I know the powers that be want inclusive education, we are nowhere near that, the number of ALN children I know have been bullied or excluded in mainstream, and some become NEET, sad state of affairs.
- . I recently learned that all schools get equal visits from the Educational Psychologists each year. So if your school has 400 pupils with 25% with suspected ALN's -100 pupils but a smaller school of 200 has 50, you get the same number of Ed psych visits. Which means that wait times are longer in larger schools. Schools struggle with this. So don't schools need to be allocated according to pupil numbers? Otherwise diagnosis will slow down and the children in large schools won't have equity with other schools.
 - *Parent/carer reply: It might vary from county to county.. something to look into.. our personal experience of EP's is that they're gatekeeper?*
 - *Author reply: In what way a gatekeeper? What are they stopping happening? My experience of our areas assessment process isn't good at all. I've been asking about my child for 8 years since they were 4 and now we have a partial diagnosis of autism and are waiting for the ADHD assessment which was bungled due to misinformation for the council team.*
- . The fact that they are automatically excluded from mainstream lessons and exams is unfair when some are perfectly capable of doing them. Having a disability doesn't make you a dunce, and if any issues do come up then support them. Don't exclude them because the system is so useless they can't be helped.
- . No. The lift is constantly out of order at my child's school, so wheelchair users can't access some lessons and are frequently left doing the work in isolation from the main class. Lessons missed include drama, art and music which require teamwork to succeed.

- . In terms of childcare I would say no. Government won't pay sufficient to cover a one to one in private childcare.
- . Nowhere you can use childcare vouchers for disabled kids. Penalises parents who then can't use the savings (I'm now having to get mine refunded, less tax so worth less)
- . It would take me all day, to type the absolutely horrific way my child was treated in education. I wish I knew what I know now, back when they were in education, I will say if I heard "I'm sorry the child slipped through the net", any more I would be in prison for murder xxx
- . I applied for a job and asked the wrap around at primary if my son could attend. They said it was difficult because my son finished 10 minutes earlier due to being in a unit as well as the cost for a 1:1.
- . I really want to feed into this. It's so difficult to fit everything in but it is important. I hope they will have a consultation event in Swansea area. Would be interested in attending that.
- . Both of my girls have lost years of education through lack of their needs. My son however had his needs met when he was really young. The difference in treatment is really clear.
- . I think things are beginning to change .for the better support from early intervention but it's all in the process. And the waiting time is long for some referrals.
- . Every parent of a disabled child has to fight. Or doesn't know their rights as a parent or how to address things on their own.
- . As parents of a disabled child we have to do our own research of what is best and stand for what we believe in. It can be a fight but if we stand for what we believe in things can be put in place x.
- . At the moment they don't have an equal right to education. This is due to certain schools knowledge possibly funding. More training is needed, referrals being left too late some children are missed until later through the school. IDP are great being started at early years but every school needs to support the child and provide the best outcomes so children are not left out of their education.

- . When my daughter was mainstream the primary school really did their best to accommodate her needs, in class and on trips. A neighbour's son (ASD) attended the same school and they "shipped him out" to a unit. Why did this happen, why did they not do the same for him as they did my daughter? She is now in SEN/ALN school and fair play the staff are great and she is improving. BUT..... The school should have had a purpose built brand new school open September 2022. That has been delayed because the "goal posts" have been moved and its now due to open spring 2025, yes THREE YEARS LATER. The site of the new school hasn't even been cleared so I can't see it opening in barely 18 months' time. While this is being delayed there are apparently plans going through for a main stream school to have a 2nd extension built (the first is no more than about 7 or 8 years as old). In my view it's bordering on disability discrimination by the local education authority. SEN/ALN education provision really needs sorting by local authorities as well as by the Senedd, its falling behind at an alarming rate and it not good enough.
- . My daughter had a torrid time in school, every recommendation put in place was followed for a week then abandoned. It's a huge trauma to both of us, the arguing and fighting just for her to have basic needs met. My other daughter has just dropped out of uni after her isp wasn't followed at all. I can complain but what is the point? Right now my focus is my daughters mental health after once again being made to feel stupid because she has a disability. It's absolutely heartbreaking.

The extent to which children and young people have been excluded from aspects of education or childcare due to their disability or neurodivergence.

- . My child did not start mainstream primary school until 6 months into the term because the funding that was allocated for the primary school to put a wheelchair lift in so they could access the canteen and assembly hall was taken away and given to another school by our LEA. They did not deem my child's access to education as a priority so moved the funding to another school. We were not told until a week before they were due to start school. After exhausting complaining the head of the LEA came to our house to apologise and moneys were found and my child started school months into term. Primary mainstream was a constant battle as the LEA did not provide the school with the provisions they needed to

enable my child to access an education I had support a few times from the children Commissioner for Wales as once they got involved the LEA seemed to jump into action. It shouldn't be like this. It is exhausting and so stressful as a parent and unfair to the children involved.

- . Physically disabled child is not included in PE at all. Often watches a lesson from the side, or does paper based work instead. A wider range of activities included in PE such as Boccia or Pickle Ball would make inclusion easier and appropriate PE lessons would reduce the need for therapy at alternative times. At a minimum wheelchair users should be encouraged to move in the lesson, but this is often not the case.
- . My disabled son was in his primary school from year one to year six. The school didn't plan for him to attend his year 6 residential and I had to push for it and mention discrimination before they sorted it. This was all done less than two weeks beforehand. I had done my homework by arranging with the place where the residential was taking place. Another deaf child in his unit also attended but wasn't physically or learning disabled – his TA knew for months beforehand that they would be going. I was told that due to how they had organised the staffing my son wouldn't have support for the evenings and overnight. He went on the residential, because I mentioned discrimination and it was an amazing time.
- . We didn't receive the letter asking my son to audition for violin lessons. My son asked me about it when he saw one of his peers with a violin. I asked and was told sorry all spaces have gone now. I said that I would buy a violin. They reluctantly gave my son an audition and he was supported by his TA who had never played a musical instrument. He failed the audition – no reasonable adjustments.
- . My son was steered to the unit to eat his lunch and not the school canteen like everyone else. I think this was because of staffing issues. Mainstream children who weren't allocated a space in the unit were not allowed to go to the unit so therefore my son hardly ever got to have lunch with his friends.

To what extent are children able to access their local mainstream school? Especially if they are learning disabled or neurodiverse.

- . My child wasn't welcome in a mainstream school unless they could be organised into an unit... so looking from a social model point of view the barriers are actually the system ...
 - *Parent/carer1 reply: basically it's pants ! It's a pants system!*
 - *Parent/carer2 reply: your child got a free education from aged 4-16. So many are not that lucky. Mine wasn't, and among their peers I've now witnessed one too many suicide attempts, compared to the kids lucky enough to get a specialist unit place who have been able to fulfill their full potential as happy young adults. From where I am standing your kid has been one of the lucky ones.*
- . Can access mainstream but only if my child masks their difficulties and differences in order to survive.
 - *Parent/carer reply: Ditto to that, but attendance down to 40% at point of GCSE exams, due to sensory intolerances and school related anxiety, so by no means a level playing field 🤔. Been banging my head against brick wall since pre-primary school 🤔*
 - *Author reply: never ending*
- . My child went to a mainstream primary school that didn't pick up on their additional needs at all and put their meltdowns down to behavioural issues. Child was put on reward charts, time out in their sensory room and also excluded from school. Their meltdowns got so severe by year 6 that one meltdown was very big and distressing for everyone in class I wasn't included in the decision but when child moved to comp they were put in the provisional unit. On their first day child was given the mainstream timetable but they then gave child a different one the next day. Child was upset as it was missing the lessons they wanted to do like drama and art, and none of their friends from primary school were in any of the lessons. When the meltdowns started again I rang the school and demanded child be assessed as I knew from experience that they would escalate. As child didn't have a diagnosis they had regular meltdowns, not helped by several kids bullying them. Child started with one teacher, then was split between the two teachers, then moved to the second teacher. They were then bullied by kids in both classes and missed part of lessons from constantly switching so got confused as they lost track of the lessons. Child also had their worst meltdown in the

provisional unit itself which resulted in child being excluded as they switched the teacher's computer off at the socket to stop the teacher from reporting it several times which blew the hard drive. All of the signs that child was getting distressed were missed by the staff and child can't talk when they gets really upset. The meeting which assessed it was likely they had autism and ADHD was in the January when they were in year 8 but ND Pathway has a 2 year waiting list. The educational psychologist said for the school to put the support in place as if child had a statement and it did help as they acknowledged child wasn't just misbehaving. Child finally received a full diagnosis last October which also included Oppositional Defiant Disorder which was the main trigger of the meltdowns. Child is now also taking Medikinet XL for her ADHD. However, another potential issue has arisen as instead of mainstream GCSE subjects the provisional unit is put on the pathway program which is mostly Btec qualifications. It's because "they have issues with revision and find exams overwhelming" which is a very sweeping and rather ableist statement. The level 2 childcare course requires 3 GCSEs to be accepted which has to be at least a D in English language and 2 C's. Unless you do intermediate maths you can only achieve a maximum D grade they also said at the interview that they don't accept the BTEC qualifications to get on the course. If this is the case then you are potentially excluding any pupil who was put on pathway if they don't achieve the grades in maths, science and English language as those are the only GCSE exams they sit. The entire system works against children with additional needs. Even in the provisional unit the teachers' knowledge of the conditions seems to be nonexistent, and it's even worse with the mainstream teachers. Instead the textbook symptoms gets punished for as they are seen as behaviour issues. One teacher in particular gives negative class points because my child gets up constantly, talks over him, doesn't make eye contact and doesn't do what he asks. He is very abrupt and confrontational when he talks to child which triggers the ODD and child hates him. His ignorance is obnoxious and he is totally the wrong person to be in charge of pupils with specific requirements to feel safe. It should be compulsory as part of teacher training to learn about neurodivergent conditions especially in the provisional unit.

- . It's difficult through all the stages of education. Primary schools don't know how to help so don't like to accept them, secondary schools don't like the attendance rate or failing as they call it on their records when it comes to GCSE time and College is the same. It's a mine field and full of

rejections and depriving of their rights to get qualifications. Equal rights does not exist in education for our children.

- . They can access it in the sense they can go in the building past that it's very much down to the ethos of the school, individual teachers and funding by the LA whether it works but that's at individual child and school level I don't think it can be generalised.
- . I come up against battles daily that my child should not be in mainstream and get lots of comments that they would be better off in a unit. The unit however would be miles away not in the local school with their friends.
- . I am up all night. Every night. We don't meet the "criteria for help"
- . You also get the converse problem where a child is in the unit for an issue where they should be mainstream but the only excess capacity is unit/hub/resource base, so in they go never to be seen again.
- . My child wasn't welcome in a mainstream school not welcome in a unit as they **didn't** have a learning disability. The disabilities are autism and sensory issues. The poor lack of understanding was terrible, I feel staff and teachers just wanted to take the easy route out not wanting to do the job and easier to make me sit in class with child, reduce their school day and eventually kick them out of school all together.
- . My child was doing great in mainstream primary. I had to move child to special school for secondary as there was no provision in mainstream. Special school has been awful. Child hasn't really come on at all. Im now looking elsewhere for another school.
- . My child went to a mainstream primary and on the whole they were very good with them. Child's classmates were very kind and supportive as some had known them from nursery. Child is now in SEN provision as everyone agreed they would not cope in mainstream secondary.
- . Specialist units are restricted in numbers, it's usually a fight to get one. So more ASD/LD kids by default attend mainstream, usually with access to a t.a. so shared support if they are lucky. Unless severely disabled then complex special school placement

- . My child was in one school and it was awful. They point blank refused to recognise the diagnosis and communication was nonexistent. We moved child to another secondary school and they're a different child. They're happier and they are brilliant with what child needs on the day. There's a bigger plan in place for over the year but they all understand child doesn't need babying they need space to emote on some days and not so much on other days.
- . Patchy and no joining up at all. Most "ALNCOs" and other staff have their own interpretation of the new ALN bill which is extremely flawed. No support or limited as if you're in the mainstream and want to do a higher level of vocational training they assume you can cope. No educational Psychologist provisions in local college either.
- . My child has been in mainstream with full one to one support throughout his schooling. Child is year 10 now but both the primary and secondary school have been great. Child doesn't have any difficulties with learning or behaviour though which I think helps.
- . So depends on staff tbh.
- . Not. They didn't acknowledge child's difficulties, meant autistic burnout 2 years ago. No School since then.
- . For some children mainstream will NEVER be accessible, no matter how many accommodations are made. My child was one of the tiny demographic for whom not only was mainstream inaccessible, it was cruel and traumatizing. So traumatizing that it left child unable to even access the wonderful specialist teaching facilities that abound in our area. There is no mental health support whatsoever available for these traumatized kids who are now left dealing with secondary mental health conditions such as anxiety disorders and PTSD on top of the struggles created by their original disability
 Much as I wish it were otherwise, child is far from being an exceptional case, and one of the reasons for the depressingly high suicide rate among some types of neuro divergencies and cognitive vulnerabilities is because of this ridiculous drive for an unrealistic "inclusiveness" that requires that we bully square pegs into round holes.
 The goal of education should be to support a child's needs such that eventually they can meet the demands of mainstream adult society. That often means very specialist expertise and labour-intensive support

during their formative years to get them to the point where they have the skill set, both vocationally and socially to be employable, the life skills to live independently etc, etc. If anything we need more specialist units to teach braille, provide intensive speech and language interventions, low sensory demands, occupational and physical therapies that are fully integrated into supporting academic learning & emotional skills training etc.

It's possible to provide that through the unit model, but it's just not possible in mainstream, as has been tried and tested and seen to be utterly inadequate via models such as Langdon in Newham borough, London. Why push for a failed model? Why not push for more and ever-improving specialist teaching facilities capable of giving kids the support they really need to make it as emotionally healthy, employable adults capable of living as independently as their full potential allows, taking into account the limitations imposed by their disability? This model of a faux-inclusive childhood, followed by an unsupported and lonely adulthood wholly dependent on the whims of a capricious welfare state is not one I'll ever be a fan of.

That does NOT mean to say that every mainstream school should not try to be as inclusive as is possible, on each and every available occasion, from the design of the school building itself to much-improved staff training, right through to encouraging and supporting parents to work in constructive partnership wherever possible. Anti-bullying policies also need to be very robust indeed, because sadly children do need to be explicitly taught to be kind to those who may be different from themselves, whether it is because of their faith, disability, gender orientation, socio-economic status, language barrier, skin colour, body shape or whatever. Sadly kids are herd animals with an incredible ability to ruthlessly reject and pick on any herd outliers.

At the moment what's happening is that year on year more and more children are being forced out of the state system altogether, and their parents are having to take on the full burden of providing an education, a therapeutically healing & stimulating environment including appropriate interactions with peers, etc alone, with zero support, funding or respite. This is leading to families and children in crisis, and we have to do everything we can to turn this dysfunctional ship around.

The right to a state education is far from universal, no matter what BS the politicians feed us. It needs first to be recognized that it is a privilege for any child to get a state education, and even more so of one to gain admission to a specialist teaching facility; where a child might hope to be properly educated instead of just babysat. Only then can we start to

address the inequalities being created by the recent huge increase of children being off-rolled and forced into home education, especially in the midst of a wider cost of living crisis when the loss of an adult income to the home can and does lead to homelessness. The Tories call this cohort "ghost children" because that is what so many become, invisible to all service providers, and doomed to an adult life of poverty, social exclusion and dependency as a result.

- *Parent/carer reply: totally agree with this. Inclusion as an ideal is great but there is no way you would ever fit my child into a huge school child just can't cope with that. What frustrates me is the refusal of some to see that just because inclusion is the ideal in reality many of these children don't want that themselves and often end up with trauma, EBSA or permanent exclusion.*

- . My child is in welsh school and it was difficult to begin with as the teachers did not want to fail my child!

What are the issues for children with multiple disabilities?

- . They only deal with the disability they know about - or think they do. My child's primary brain injury diagnosis has been completely ignored as they have no experience in favour of the secondary, ASD, where they already have things set up.
 - *Author reply: Don't get me started on that one this early in the day there are no services for kids in Wales post discharge for brain injury let alone any sort of training for schools*
- . I very quickly learned "complex needs" translates into meaning nobody has a clue what to do, so opt to do nothing.
- . Child is deaf, physically disabled and learning disabled etc etc ..2 rare genetic conditions...in lots of the forms you have to decide which one is the overriding issue..had to choose it as a category for their educational statement
 - *Parent/carer reply: You would think as they overhauled the statement and replaced it with the ALN Education Plan that it should have been made so it does support every diagnosis. That would be far too logical.*

- . My child would come under this so multiply appointments during school time that nobody is bothered about as it doesn't matter if child is in school.
 - Parent/carer reply: *that's the worst thing. That nobody thinks it matters. Its dehumanising*
- . *They pick which issue they want to focus on. My child has multiple MH conditions.*
- . The problem starts by quickly labelling someone with “complex medical needs” or “neurodivergent” and the box gets shut on it. Rather than a child who has additional needs and requirements to function appropriately. The problem gets chucked at the condition rather than concentrating on the solution to regulate or accessibility. My child sees their condition as a super power that comes with issues others don't or won't get impacted by. The school support this in child and as a result child has managed to access all their classes and social circles. Because of this child is thriving in school. But the school we removed child from didn't recognise the diagnosis but used it as a reason to stunt their learning and growing. Child was miserable and very depressed. They're like a different person now x
- . Well, most of them are ignored in favour for whichever is cheapest/easiest to resolve. There is no recognition of how they affect each other or make things more complex. The person (child) is overlooked and instead the disabilities become the focus.
- . Services are rationed to child because they're learning disabled
- . Child was never systematically afforded BSL even though they're deaf
- . Cerebral palsy, adhd, add, epilepsy (awaiting 2nd asd assessment) developmental delay. While in main stream primary they done their best but by god it was a fight. We often found we were having to explain each thing... separately.... several times. Now in SEN/ALN school and with the (shall we say) complexities they can occasionally find child awkward but they do have a much much better understanding.
- . I also found after years n years regular check ups in many different clinics once 18 back to care if GP luckily ours are great but some families struggling

- . Where shall I start.....
- . My son has 2 rare genetic progressive conditions. His impairments are significant. He is in mainstream education and it is hard for staff to support him without me working together with them as a team. School and college have not wanted me involved much and this has caused issues. I go to all his hospital appointments and know how his body and mind works so need to observe him myself in a situation. When I have been able to do so we've been able to troubleshoot quickly. My son cannot tell me much of what happens and he tells me in dribs and drabs. He will always nod and smile when questions are asked of him- staff think he's understood what they've said but he hasn't always or that he needs to be told a few times before he has got it. Filtering me out isn't sensible.

To what extent is there unconscious bias and what impact does this have?

- . Personal experience, if they're not disruptive or causing havoc, there is no need to provide for their needs. That quietness/shyness/shutdown/withdrawal is okay.
- . Nobody asks my disabled son what he wants to do when he grows up. There is little aspiration for him.
- . Assuming they are less able physically and cognitively is the biggie for me. My child was in a science class in secondary in their wheelchair and was not able to access the lesson properly because the school had not attempted to differentiate the lessons. Child was accidentally filming on their iPad which they use for communication and I saw this video a few days later. You could see the science teacher showing a practical and the class watching. He was asking questions and none of the kids were answering except for my child on the iPad. The teacher said to the class that they all needed to take a leaf out of my child's book and pay attention in class. The thing that made me anger was due to the failure of the school and the LEA and the whole system my child never accessed a secondary education and came away from secondary school with

nothing except social skills. They were all definitely unconsciously biased that because my child could not talk or walk that child couldn't understand the work.

- . I think it is constant. Right the way through primary they have been 'surprised'. An assumption of inability. "Can they count to 20?" asks the Reception teacher when child could count to 300 in Nursery (at the time child had little language other than numbers - it was their thing). A lack of expectation I think largely because of a lack of experience as our kids aren't present enough in mainstream.
- . Can I come in on the other side for conscious bias? Where education is absolutely aware there is a disability and are 1000% convinced that by not providing support because on the face of it, the learner can cope, they are actually doing them some sort of twisted favour by forcing them to be resilient.
 - *Parent/carer1 reply: this!!!! 🏠*
 - *Parent/carer2 reply: but possibly also setting them up for after school distress and meltdowns due to unmet needs and longer term burnout? Unfortunately the bias is to what they can see with their own eyes rather than believing what they are told is reality from those who know them best.*
 - *Author reply: singing to the choir over here. I've seen more than one need CAMHS and YIT intervention due to stupid, easy, available adaptations like extra time.*
 - *Parent/carer2 reply: I agree. My child was applauded by the Senco who said he admired child for not wanting extra support! Child needed support but was made to feel different and stand out so learned to keep their head down. Why is this something to applaud?*
- . I would say that there's definitely unconscious bias in cases of invisible disability especially when combined with good academic capability.
- . The use of language in reports home about behaviour when dysregulated. In risk assessments and IDP and in referrals to professionals. E.g. 'attacks', 'aggression and 'controlling'. All demonstrate lack of understanding.
- . If they are cognitively able and verbally able to answer questions this should be counted not making them write when physically unable. Also

differentiating in comp so they access all the curriculum. More qualifications that at skill based not test based xxx

- . Personal experience with polar opposite child to one mentioned above - too many behavioural needs, pushed into home education. Bias that they're difficult and challenging so must not be able to learn.

To what extent are teachers and support staff trained to support disabled children?

- . I used to push for training etc yet after 12 years I've come to the conclusion that apart from medical things, eg diabetes, you can't train what most of our kids need which is someone who is empathetic, wants to learn about what that individual child needs by working with them and can think on their feet. You can't train that into people it's a natural skill and I think in hindsight I should have concentrated more on insisting they found the person with the right personal skills than the one with the right certificate and could use buzzwords. You can't train on a course, or document in a statement, eg someone to see that a child is starting to get agitated. Every child is different, which I hear all the time, yet by some miracle we expect them to go on a course and it will teach them to me manage every child. And if I argue with one more teacher with an "I've been on a course so I know everything" attitude I will scream.
 - Parent/carer reply: *The sweeping attitude of all neurodivergent kids are the same is incredibly ableist too. My child is fed up of being told they can't do this, that and the other because they find it too hard. Teach in a way they understand then and not the neurotypical way and then it won't be!!*
 - Author reply: *that's my point and you cannot get that through in a day course. Parents, and I did it, push for courses etc yet what they actually need is someone to look at their actual needs and meet those rather than going by a generic tickbox exercise they learn on a course. The course gives the sweeping attitude because they are led to believe that a course tells them everything. There is no way a course can provide a teacher with the skills needed they come from experience and natural ability to react to what they see rather than what a trainer tells them they will find. One of the most helpful people I ever met said to me straight off they have no experience in*

SEN but would do their best and it worked because they had no preconceived ideas as to what child's needs would be and had the willingness to establish what they were and work on them.

- *Parent/carer reply: We have to learn too and yes mistakes happen, but there needs to be a lot more understanding.*
- *Author reply: I don't think you can get that from a course though how can you understand the huge span of needs. Take a difference example it's like my child has a brain injury. The span of that is from being in a coma to those with just "minor" issues. How could you possibly go on a course that could show you in a day how to deal with both of those and anything in the middle? You can't and unless they wanted to do a whole neurology course over years it's not realistic to. The understanding needs to be that every child they meet will have different needs and those can only be found out and met by working carefully with the child, acknowledging and getting advice if they find something they aren't sure of, and from a higher level that the correct person with the personal skills who can build a relationship with that child needs to be found to do that.*
- *Parent/carer reply: They could just talk to us to ask as we know them best 😊*
- *Author reply: that's getting acknowledging and getting advice. I think it's part of the mindset of schools that they are told they shouldn't ask parents for advice because it's admitting they don't know when they want to be viewed as experts*
- *Parent/carer reply: The thing is there is plenty of information available as we go from knowing nothing ourselves. Maybe they should ask organisations like the National Autistic Society for advice as surely they could come up with even a basic package. Anything would be better than the current system.*
- *Author reply: it's the same with all disabilities not just ND ones.*
- *Parent/carer reply: I know but I am back in work so that was the first one that came to mind 😊*
- *Author reply: it's all a complete mess tbh. Half the problem is that SEN is now seen as ND ignoring everything else and the other is they employ any LSA that applies as the wages are so low people don't apply. In high sch it's made worse because LSA are not assigned to a specific pupil. It needs a complete shake up and the new ALN system lacks any accountability at all which was the main fault with the old one. I didn't really look at the ALN stuff until recently I just didn't have the headspace for it but am shocked that so many parent groups were involved saying it was great when it's*

awful and anyone with even limited knowledge should have seen it was a car crash waiting to happen. I'm just glad we are almost out the other end of it

- *Parent/carer reply: Having an education plan seems to make no difference either as my child had their one year review but the English teacher was appalling with his attitude towards child. He clearly didn't acknowledge it at all.*
 - *Author reply: we've had a statement since the start and it has made no difference. I think half of the problem is you can't describe my child on paper because their functioning levels and what they react to are so dependent on environment etc which is why I think the LSA needs to be consistent so they can get to the point they can read that child and be proactive rather than reactive.*
 - *Parent/carer reply: They need to understand sensory processing issues can change from one room to another.*
- . I find even when offered free training schools are reluctant to take up as it means releasing staff. Some staff are amazing and taking on the task of learning about conditions, bsl etc them selves
- *Parent/carer reply: seconded. This is also my experience*
- . They are trained at all? Since when as I have only come across a lot of complete ignorance. My favourite comment was "yes we understand child has been recently diagnosed". No, you don't understand at all or I wouldn't have had to complain yet again about the disgraceful attitude of your teacher. He definitely doesn't understand as he dishes out negative class points like Smarties for "behaviour issues" which are textbook symptoms of conditions.
- . Lack of training for taxi staff assisting with physical transfers for wheelchair users.
- . No allowance made for training staff in taxis. Multiple times child can't go to school as child needs suctioning and there's been no training for the escort. Child will likely be fine the rest of the day.
- . Taxi staff providing transport to school do not seem to be given any training on the needs of the students. Is there any guidance on recruitment of taxi escorts? If an escort does not know appropriate ways of interacting with a child and continues to trigger poor responses from the child what safeguards are in place to protect the child? Lack of training causes direct harm to the child.

- . I feel very few teachers properly understand neurodiverse children and the fact they all present differently. Teaching assistants can be and are trained for physical disabilities but it tends to be only those who are directly involved with the child.
- . I don't believe they are trained at all. In my experience teachers had very little understanding of neurodiversity including the SEN. I haven't been on a course but read enough to understand what are the issues and how to educate and support a child with additional learning needs. You then apply those to the individual child. Even a basic understanding would help but it's just not there (we had a bad experience as you can probably tell as many others do).
- . Teaching and support staff present as experts on disability having met one child, but they don't realise that every child and disability is individual.
- . When a child has a mental health problem the GP directs the parent to school as a route to access CAMHS. School staff do not have medical training, and the mental health issue may not be visible to staff at the school. This does not seem the most effective, safe or private route for mental health care.
- . So many comments here that chime with me. Empathy, a will to understand, seeing inclusion as a right and willingness to be flexible. Versus curriculum, dated teaching practices, autocracy. The former is needed way more than the latter. Whether it is teachable or innate is a really good question.
- . It's poor, a day in teacher training , t.a.'s can access basic ASD courses , but it is not mandatory for any staff members to. I would hope at a minimum alnco's continue to develop their practice with continued professional development training in areas of a wide range of disability. All staff need to have a minimum knowledge and annual updating . Woefully inadequate sadly relies on individuals interest and motivation.
- . When my child was in mainstream teachers weren't trained at all. Both TAs did have experience with SEN kiddies though. I have to say that the teachers and SENCO went out of their way to learn. There was also an

outreach team from one of the special schools who came in regularly to help with curriculum planning and support.

How desirable is it to have a fully inclusive education system in Wales? I mean properly inclusive..the right to have your cake and eat it in a fully accessible building for physical and neuro diverse needs.. valuing..belonging..no fights over access or support ...teachers who can teach all children regardless of learning needs

- . Part of the problem we have atm is that the powers that be believe that parents want special schools and segregation as a choice...it isnt actually a choice...its a bit like asking a starving and thirsty person to choose between water and bread!
 - Parent/carer reply: *exactly x but until it's fixed we are having to weigh up what is in our child's best interests x*
- . I don't believe the kids in main stream or specialist facilities are having their needs met either. And this is with or without ALN. I think the true numbers of people with neurodevelopmental disorders are massively higher than the stats declared and I don't believe society will ever become more inclusive of neurodiversity whilst we continue to segregate, delay diagnosis and pretend we are talking about mental health openly whilst simultaneously asking parents if they want that child to be 'labelled' with that condition. We need a much more proactive approach from health visitors, crèche and nursery teachers etc. and far, far more training which is integrated between health and education at a much younger age in a child's life, earlier intervention and monitoring of the effectiveness of it.
 - Parent/carer reply: *it's not just neurodiverse .. it really isn't* 😞
- . Hope this doesn't offend. Square pegs don't fit in round holes no matter how hard you try. As some will never flourish or reach potential in a 30 plus cohort, in a room with strip lights, bright colours and other overwhelming stimuli. Secondary schools are worse every child is expected to do the same as everyone else. They are like factories.my child is not in mainstream because child is an individual not a cog in a machine.

- . It shouldn't have to be a right for children to be able to have the same access to schools. It should be a given that it is included. Disabilities aren't a choice that you can switch off or grow out of so the accommodation needs to be there throughout their time in school.
- . I'm not massively for it. As said above. Square pegs and round holes. In comp you're separated early depending on your academic ability because of differing needs. My two children have massively different needs and I don't see how one school could accommodate both. And honestly I imagine the cost would be exorbitant and probably deplete the experience for all.
- . That should be the goal because it would reflect society and the NT kids would benefit massively.
- . It would be very desirable, with the right staff, resources, adaptations bringing acceptance and inclusion. Every school would need to be included. It just feels like a pipe dream
- . So school would reflect everyone rather than just a narrow focus on academia ... in the UNCRPD it states that there shouldn't be any segregated settings. Units and streaming too ... this isn't even in the plans ...mainstream schools would not exist... imagine that!
- . We have never had inclusive education system in Wales..not in the UK nor many places around the world ... it is gaining traction in some places ...Spain and Ireland are ones to watch
- . It's highly undesirable! The true prize is to be able to take an active, productive role in one's community during adult life and in order to do that specialist help, facilities and environments, and interventions MUST be provided during a child's formative years. Welsh specialist teaching units and schools give so many children the opportunity to learn, grow and thrive in a way that is simply not possible in other parts of the UK that don't have them. It's a key strength of the Welsh system, & we should fight to retain and expand our specialist teaching facilities at all costs for future generations. That these special units and schools exist is a blessing, and I am made so keenly aware of that fact, every time I talk to friends and acquaintances in England. By their late teens the harm done to those kids who have gone thru mainstream in the interests of "inclusivity" is clearly apparent, compared to their Welsh peers. Where

with the right support they could have been employable, emotionally stable adults, the myth of "inclusivity" has meant instead they only have miserable futures ahead of them in mental health wards, rehab units, and prison cells. Further and Higher Education is wholly selective, so if a child isn't given help prior to the end of CSA, it's too damn late.

How well disabled and neurodivergent children and their families are consulted or informed of the choices in education or childcare available to them.

- . No we are not. you have to find out for yourself and fight.
- . Not at all. In fact no provision was the option given to us. I.e. exclusion on a part time timetable. Our 6 year old neurodivergent child was not welcome / needs could not be met. Despite the IDP requiring update on basis of professional reports having been received that clearly stated needs and recommendations. It just seems to be felt a mainstream Welsh school is not up to this. Subsequent staff training has helped but the culture change needed is massive.
- . Discussion with the ALNCo at secondary school has been very open and frequent. At the beginning they took time to understand the child's needs both academically and socially. This has helped build trust and made it easier to identify the cause of problems and work towards the best solutions. By working together it has avoided wasting a lot of time with misunderstandings.
- . Well considering the decision to put child in the provisional unit didn't even include me, I would say not much.

Whether parents of disabled and neurodivergent children and the children themselves receive effective information and support from local authorities and schools

- . Can you send them a 20 minute video of me laughing as I post screenshots of all the advice I've had to correct? It will include such gems as 'we can only review a statement once a year' and 'they can't be autistic because they aren't learning disabled'.

- Parent/carer reply: *ive had in response to asking for reports two weeks before annual review "we dont do that".*

They also didnt turn up to the meeting itself it was just me and the teacher!

Also when i have asked to review the IEP they didnt know what that was. Said they didnt know what a FOI request was either. Special school too.

- . I've spent 3 years emailing school, LA and everybody in between trying to access appropriate and timely support..been bounced back and forth...had to find out about available support myself via other parents and through support groups ...had to contact agencies/departments myself begging for support. I may get a response...yes we'll escalate this and get back to you...rarely get back to me. 3 years in and the waiting for someone to coordinate response, fill in forms, email me back, etc. has caused more emotional damage to both me and my child. It really wasn't a massive deal in the beginning! A little bit of adjusting, listening, acting on the information I was giving. We wouldn't be in the massive mess we are in now. So a massive NO I have never received effective information or support from the LA or from school...until now that is!! When things got serious, I mentioned legal advice...I contacted authority AGAIN to say I'd found out about the new role of 'engagement officers 'then we got one and she is FANTASTIC!!! But it's taken 3 years of begging anyone and everyone! School told me to go look at a different school...to bring my child to school whether child likes it or not...! IDP refused by ALNCO...no pastoral support to get child into school 'because child's not in school! ' No contact from EWO until I rang LA to ask for support from EWO...couple of visits...nice chat/supportive...then nothing! Now he's left! Months of non-attendance and no contact from school to check up in child. No attempt to ensure continuation of child's education whilst battling the school trauma based phobia! I don't trust anyone anymore to do what they say. And it takes so long! 3 years of my child's education wasted by a bullying ALNCO who wanted to get rid of us...which is why they don't want to give you advice and support. They hope you'll give up and leave. My child went to form period for the first time for many many months, the form tutor ignored him!! 😞

- Parent/carer reply: *yup when my child came home with a life threatening injury i called the head and his reponse was "you can just find another school then". Appalling.*

- . No.
- . No it's like banging your head against a brick wall. My child finished year 11 last week but will potentially not achieve the grade in maths they require to get into college. Child did her foundation GCSE last November and got the D, so was meant to be learning intermediate maths to achieve a C grade. However, child was unable to answer some of the questions as they hadn't been taught how to do it. I contacted the school several times but it was too late by the time they got their act together. Even with a diagnosis and ALN Education Plan for a year the system failed child.

Whether disabled and neurodivergent children and parents of disabled and neurodivergent children have the same level of choice as other children and parents and what issues affect choice or school or childcare.

- . No wrap around care. See other answers, Also for wherever it fits best. Special school is beyond underfunded, tired and has no parking considering it's cohort pretty much all need taxis. How is a special school in such a state? Why did parents have to fundraise for the pool which is massively needed for these children? The people are wonderful but it's in a terrible state. A mainstream school would t be left like that.
 - Parent/carer reply: *totally.. I'm shocked with the funding .. this is actually because of the dual education system*
- . Poor understanding of needs and behaviour related to ND leading to excessive exclusions including use of part time timetables, outside of due process and parents experiencing significant pressure to agree to these. Reduced staffing in after school clubs making these inaccessible so no wrap around for working parents of ND children.
- . Told at 3 years old, that child wouldn't be able to go to the same comprehensive school as their sister because of the amount of stairs there.
- . No after school provision
 - No holiday provision
 - No school trips
 - Lots of facilities but years after covid still cant use them.

No holiday provision for disabled kids in cardiff after funding removed in 2020.

No childcare for complex needs kiddies (in my experience)

No access or very little access to playgrounds for wheelchair users.

No activities for wheelchair users in cardiff bay fun park summer hols.

Only one respite facility in cardiff which currently has an 8 year waiting list.

Lots of nos here.

- Parent/carer reply: *seeing it listed like that its the stark reality that disabled children are VERY disadvantaged here in wales.*

The extent to which there is adequate provision for children with different types of disabilities.

- . I sense, despite paucity of provision, greater empathy and understanding for visible disabilities than ND ALN.
 - Parent/carer reply: *behaviour misunderstanding*
 - Parent/carer reply: *with my child who is learning and physically disabled.. there are presumptions they can't achieve .. or only needs to be cared for*
- . The school system is segregated based on ability... there is a presumption that provision isn't in mainstream therefore it should be in special but often it just isn't anywhere
 - Parent/carer reply: *the othering is real.*
- . There is a severe lack of ALN school places, which are needed as mainstream schools are too big and set on targets to accommodate neurodiverse/disabled children. Wrap round care can be very difficult to get. Were told by 0-25 social worker there was nothing they could offer apart from a Saturday club in Carmarthen that has a waiting list. Was told to Google charities.
- . No wrap around care for severely disabled or complex children at all. I'd pay for a nursery if I thought he'd get the interaction but it's just not there. No summer care, social services teams go on holiday so any help is depleted. Much of the ALN provision seems to be aimed at neurodiverse/autism (not saying there's much of that either)

- . Teachers in special schools and units often have a general teaching degree.. I asked a friend who teaches in one... I asked if they had extra training and they said no not really.
- . Even in a special school staff have not been proactive with my child. Injury and neglectful practice had to be investigated by SS after a life threatening injury. School closed ranks and was told that i could just remove my child "if i wasn't happy". I did complain to OFSTED but never received a response. Abuse happens in special schools but parents aren't believed and are actively accused and investigated when they bring up concerns. Not only that but trying to get child's statement adhered to was also a challenge. Trying to get SALT has been a huge challenge even though therapists work on site. Again a great deal of stonewalling ignoring my concerns. Also school refused to communicate or work with me at all with regards to my child's aggressive behaviour. They claimed they didn't know what masking in school was so again i wasn't believed. It took the EPs and CP team to effectively force co operation. Special school does not mean better school.
- . I think what my son and we needed was an 'Intervener'. My son is deafblind. I would imagine training for this role would be useful for not only deafblind. Also I feel that my son needs 'non instructed advocacy' but there is nothing available around here.
- . In my experience...the attitude of school is ...we can do a, b or c ...that's all that we're prepared to do...those are the only alternatives so if one of those doesn't work for you then go and look at a different school. They never start with the child in front of them and think how can we break down the barriers that this child is experiencing. If you don't /can't fit in with their prescribed limited options then you are accused of choosing not to engage with what they have offered! So when we argue...but what you are offering isn't going to work...then they say go somewhere else then...made to feel like you're ungrateful!!

To what extent are families and learners consulted by the school and local authorities?

- . About what? I have never been consulted - only told.

- *Parent/carer reply: same*
- I didn't get a copy of an IEP for a child on school action plus for 6 years. I might have asked for it if I'd know child was on SA+. Multiple people have been complaining about the DP provider for 6 years as their errors come with potential jail time or fines for the 'employer'. They have a second contract now. About that level.
 - *Parent/carer reply: when my child started his special placement i asked for a new IEP as child was in a different setting. They didnt know what it was. Then took me a whole term to get targets in place however, they totally ignored the last IEP child had in mainstream and put targets on there for nursery level learners. Took me another term to get decent targets in there. I also had child's first annual review where i recieved no reports from professionals and when i questioned this they told me "they dont do that". So i went with it but no one turned up to the meeting just me and the teacher! So i refused to have the review until i had the info to review. I had to complain to get it.*
 - *Author reply: I wish your story was unusual. I really do.*
 - *Parent/carer reply: i know. X*
- Depends, if you have requested support they in my case after evidence collated by all, present a statement to me , then asked to sign it off. Annual review. Special school was great I could phone anytime to check progress. Lots of communication. Home school book .
- I think either not asked or asked as a token gesture then ignored sums that one up!
- In my experience - not at all, unless it's to use against you
- Yeah welsh schools=rubbish.... the iep I got until year 5/6 were absolutely rubbish and it was never reviewed until an advocate got involved, then things got more or less as they should but I think the professional advocate would say they were still rubbish lol. Non existent in comp but still don't know the system so no paperwork saying what child has to achieve etc.
- None. My child's school is very closed when it comes to parental communication. Just trying to find out what they've done daily is a challenge.

- If they ask, it's a tick box exercise
- Can't comment on Welsh Schools, however, I have been really impressed by local College as I feel they have gotten the balance exactly right between consulting with myself and enabling and encouraging my young adult to increase their own competency at self-advocacy to its full potential. With another year to go, I am really excited to see what heights their self-advocacy skills will reach
- From secondary school onwards and now very much so at college they want to filter me completely out of the equation. I have been told that I cannot speak to TA's or LSA's directly and that I need to go more formally through the managers. Recent appointment with OT for my son in a brand new setting. I turned up but they weren't expecting me. My son politely nodded to their questions which I don't think he understood. Basically an OT who parachutes in and out and a support worker who has only known my son a couple of weeks were going to assess the situation. I was glad that I attended but I didn't really feel welcome. I don't blame the staff – I think that the system is organised this way.

The barriers for schools and childcare providers in offering accessible provision

- There's a cultural challenge for schools to accept that they could and should include children with range of SEN and / or disabilities. Particularly in Welsh medium primary schools that appear to have been left behind by local authorities.

The education Tribunal for Wales makes decisions on appeals about additional learning needs or special educational needs and claims of disability discrimination in schools. How confident do you feel about using this? Please give stories in the comments.

- There's a cultural challenge for schools to accept that they could and should include children with range of SEN and / or disabilities.

Particularly in Welsh medium primary schools that appear to have been left behind by local authorities.

- My thoughts are from experience is that most children do not benefit from this – only those whose parents feel confident or have resources/ support to do so. For all the parents that use this there's a massive % of children who aren't afforded the same chance so therefore a small % of children benefit from it and loads are let down by a system that doesn't include them...
- Going to the tribunal made the relationship with the school much worse.
- Tribunal feels out of reach and inaccessible.
- Worry about cost – I can't afford the money it takes.
- Going to ETW had created significant antibodies from school and we are worried about the impact on our child – how do we resolve that conflict within ourselves?
- I think there needs to be something about the cost. If you use a solicitor you are talking about 8k as an absolute minimum. It's really inaccessible and the LA view it as we are doing a fab job for most and we only had X tribunals – behind that X number are many families having a poor experience who cannot either afford to go to tribunal or have the mental space and energy to do so. To this day I think I have elements of PTSD from our tribunal and we were successful and that was 7 years ago. We got what we needed for our son to thrive but it was traumatic and expensive.
- I don't have the energy as a parent carer to take on the bureaucracy – Home Education has been our ONLY option
- It really affected my relationship with other parents at the school – I was kept at arm's length because it looked like I wasn't supporting the school – this lasted the whole time my son was in primary school.
- I wish that I had known about ETW when I was struggling to get the right support for my son.

- I've been to tribunal and it was extremely stressful. After tribunal your child has to go back to the school and there is such a lack of trust.
- I had support from the National Deaf Childrens society the first time around and SNAP the second time. Both times highly stressful and both mentally and physically affected me.
- The wrangle at tribunal is awful. It's like auction house bidding, I called it deal or no deal, it was haggling. 'What's your very best price?' They offered 15 hours – we refused, then they offered 22.5 hours. Then I said 'We'll see you at tribunal'- then we got 30 odd hours!
- I've definitely got PTSD from the tribunal and the whole stress of the statementing process, never mind now they're pushing it all into a crap IDP!
- First tribunal was initially for a few things..one was having a toilet close by the classroom for my son who had mobility difficulties. His classroom was the furthest classroom from the accessible toilet. There was a closer toilet that could have been altered. This was dropped and the only thing that went to tribunal was Speech and Language therapy. We had been told that because he was deaf he would be entitled to 12 hours of speech and language therapy per year including attending meetings, writing reports and liaising with staff and parents. Once they did an EP assessment and found out his learning disability they decided to cut that down to 6 hours. At tribunal he was awarded 24 hours per year based on the fact he was in a deaf unit and would have much more language development there. Over the years he has probably only received half of that. It is difficult monitor when your child struggles to communicate and school don't tell you. He has lost everything as he has gone to college and they do not provide this support. He is still learning and developing at a different pace to his same age peers. He really needs SALT and Teacher of the Deaf but there is nothing now he is at college. He is beginning to drop some speech sounds.
- Second tribunal was to allow him to go to secondary school with his peers from his mainstream primary school. He wanted to be with friends. The professionals and LEA strongly advised the local special school. I had read about the social model of disability as well as the UNCRDP and wanted to advocate for him to have inclusive education. We went to tribunal and he was allowed to go to his mainstream secondary school. The school placed him in the unit there which meant he was only 50% of

the time in mainstream (we had to put pressure on to get even that) They wanted to disapply him from Welsh, History, Geography and Music. We agreed to Welsh and History but not the other two. It is common practice to disapply deaf learners from languages, especially Welsh. You are advised that it will be detrimental for your child to learn Welsh – this is not correct advice! Only because I dropped and picked my son up was I able to educate his TA. She became his advocate in lessons. She helped the teachers along and the consequences of this was that my son came out of school with 4 GCSE's, a BTEC and an entry level. Learning/ intellectual disabled learners are completely segregated at school – even in mainstream schools they are kept separate to 'manage' them.

- My son was discriminated and kicked out of education with the comments they 'couldn't see where he fitted in' and 'it doesn't look good on our books' where they caused him to be unwanted which set off his anxiety even more. Prior to that in another school he was abused by other pupils to the point of ambulance and police being called by staff, yet no action taken against the abusers and when challenged they refused to safeguard him.
- I didn't quite get to the tribunal option, but I did have a sit down meeting with the *ALN lead* in which he lied, proved he hadn't read my sons file at all and clearly expected me to be a 'complainer' that he could make go away. This came after I was basically threatened with the panel forcing a decision on me because I wouldn't accept a MLD placement for my son when even the teachers at these units confirmed they weren't the right places for my son. I had an EP lie and state we'd had meetings where I'd agreed to these things and that she'd met and talked to my son – yet I'd never met her, never spoken to her and my son is non-verbal which she didn't know but had somehow met and talked to him. I had to ring the panel multiple times and eventually threatened to go to the press to get the panel to call me back and pushed the 8ALN lead* for a meeting (in which he said my son didn't qualify for an ASD unit because only the highest cases qualify which normally requires non-verbal and 1:1 needs – which is exactly what my sons statement says). It was incredibly stressful and I was lucky I was so angry that I stood my ground but in front of a tribunal panel of people, alone and stressed I'm not sure I could have.
- A certain person sat in a room and lied to my son's face about helping. They offered a standardised illegal blanket 15 hours hoping you'll crawl away thankfully, they offered 22.5. It was like some sick bidding war, they

realised we weren't going away and were willing to take it all the way (SNAP were amazing) they then gave what we needed to stop the tribunal. That person still makes me and my young person sick due to the lack of honesty. If you have enough health professional reports they speak for themselves but it contributed to a nervous breakdown and 8 years later I'm still bitter. Young person flourished with this support but I'm not receiving chronic pain and fatigue support from the NHS due to the carminative effect of having to fight for 15 years. It is extremely hard to trust any educational or council employed professional now. Currently disability social worker is fantastic but it's taken a long long time to trust anyone has my YP's best interest at heart, you never switch off x

- Legal aid is now incredibly restricted, meaning that many parents who would have loved to keep their children in school now give up and attempt to educate them at home with the cary carrying degrees of success instead. Schools and LA's alike seem to see this driving of individuals out of education as a success instead of the awful failure that it truly is. Key Performance Indicator's need urgent adjustment so that instead of being rewarded for off-rolling, schools and LA's get penalised in the Estyn ratings and when budgets are allocated etc. Obviously, legal aid funding needs to be massively increased to improve access to tribunal too!
 - Parent/ carer reply : *So has your child received those hours and has it been good support?*
 - Author reply : *So yes it made a massive difference, he got all those hours, he passed all his GCES's C and above apart from English but the fight has given me chronic health issues.*
- My daughter has just gone to college and has an IDP. The college have withdrawn her support because she appears to be coping. This was done without asking my daughter or including us in the decision. My daughter is not coping and has already been off a day because of the lack of support. We have the IDP and yet the college is ignoring it. We haven't got money to go to tribunal and SNAP no longer operate in our area so we aren't sure if there's anything we can do.
- Our son is traveling a year behind his age group. School and LA gave him an IDP last January. He wasn't allowed to start school without an educational statement. Welsh Government have decided that he isn't

eligible due to his age. School nor LA interpreted it this way and many people who are on top of the legislation said that it only talked about year group and not age but those responsible for roll out post 16 in WG have decided that's it. My son has significant impairments and needs things like Speech and Language therapy and teacher of the deaf but without an IDP he has no protection at all. All his friends that he travelled through school with now have this protection at college but not my son. College culture has been built on the learning and skills plan. I have read around this and it is VERY medical model and restrictive – anyway these don't really exist anymore. We only found out this fact in July when all the decisions had been made... we feel misled. We cannot even go to tribunal so how can my son have an equitable and inclusive education system.

The extent to which children and learners are currently able to access all parts of childcare and education provision, including the way in which the curriculum is taught and extra-curricular activities.

- Less education, more childcare – no. School holidays, many disabled kids cant go to sport schemes and wilderness days or play events because of their needs. Interventions or medical. As a parent I am willing to pay as I would for my other child, but the ONLY thing available is interplay which is underfunded and allows only a few days over the whole holidays. Equally he can't go to a nurse placement due to the needs he has. As a result disabled children are losing out on vital social interaction and opportunities for several months a year!
 - Parent/ carer reply 1 : *Totally agree! We are due to move to a county in Wales from a county in England and my biggest fear is the lack of activities for my children. Here they have special Club which is partly funded by a county in England short breaks but we still pay £30 for a session which is 10am-4pm in school holidays and weekends during term time. We don't get a space every day as the demand is so high but its lovely being able to allow them to be independent and to go to clubs without us there. Everything I've looked at back home requires parent/ carers to stay with the child which doesn't promote independence at all. They are most definitely discriminating against children and young adults with disabilities which is sad 😞 There are so many more available clubs and extra*

curricular activities in England This is my biggest fear about moving home. Although the children will have their cousins around them they will miss out on Gymnastics, trampolining, holiday clubs and weekend clubs. I feel that sadly Wales are very much behind the times when it comes to adequately supporting children and young adults with ALN. Looking forward to campaigning for more for our children and hopefully continuing to give them the very best opportunities to be independent and live fulfilled lives 👍

- Parent/ carer 2 : My son has managed to join mainstream activities like church clubs and scouts etc..supported by a PA via Direct Payments – this was he gets a break as I do 😊*
 - Parent / carer 1 : That's good however my son is non-verbal and although my daughter has words she's not conversational therefore we find specialist clubs far better for them. The gymnastics they go to run alongside mainstream/general there is a smaller group for AL children which is better for them as its smaller and they don't have to wait so long to have their turn etc and have 1:2 support. Neither of my children would be suitable for cubs/ beavers etc they enjoy clubs more tailored for their sensory play etc which we have found a few here in Surrey but nothing similar at home at the moment.*
 - Parent /carer 3 : I agree with first comment. I'm self employed and we've been able to use a local school summer club until now. He's just in his last year of primary. There's nothing now he can access going forward. There's nothing age appropriate for it's the security of trained staff to support him. This applies to youth clubs too. I'm sure he gets fed up being with me all the time and it doesn't help him to be with me all the time. He is very sociable and gains so much from activities.*
-
- I worry that the new ALN bill will disguise the support that has legally been identified for education for a young person by using terms such as 25 funded hours. And parent/ carers are not understanding that this is not necessarily with a TA support. The new way of writing support comes under universal provision and can be a huge grey area if clarity is not transparent and accountable. Plus schools have lost so much money due to Brexit they are running on shoe strings and universal provision will allow this to go unnoticed and you may think we are going towards inclusion but it will result in hidden barriers of exclusion for those who legally have a right to an education as any young person does. Case studies need to be seen to really understand the potential damage of the*

new bill and lack of funding in education. And understanding as there is no real understanding.

- Made the decision 15 years ago to put my son in mainstream education because I could see how much understanding he had behind his eyes and felt it would be unfair not to try mainstream. He loved every minute of mainstream school but did not access a mainstream education. The school could not accommodate the education he needed and the battle was never ending. He started Special Ed School at 17 and the school and teachers are incredible. He is loving it but I did notice he went backwards for about 6 months before moving forward. There should be more support for kids who are in between mainstream and special ed. At the moment it is unfair and totally biased towards one or the other.
- No is the simple answer. There's no childcare provision for my son so I can't work. My son's school do not do any kinds of trips or fun things outside of school despite promise of disabled horse riding, go karting and other things when I enrolled him. He's not even able to access the onsite swimming pool or wheelchair trampoline as there are always reasons to justify this. I'm looking to move him back to mainstream and experience of specialist provision so far has been horrific resulting in many injuries, one life threatening and behavioural issues due to total lack of any speech therapy or communication aids.
 - Parent/carer reply : *That sounds awful, our experience of units was brilliant in terms of them going out regularly and visiting farms and play areas.*
 - Author reply : *This is a special school and out experience has been awful. This school also consistently reported me to SS for injuries which occurred at school which resulted in a Section 47 investigation on myself. Yet, when my son sustained serious injury due to their incompetency I had to complain to the school governors and LA to even get an apology. I regret my decision to put my so into special school.*
- Also holiday schemes. My son used to be able to access holiday clubs as the council paid for 2:1 staffing. This has been removed and there is currently no holiday provision in Cardiff for disabled children with physical disabilities. The school does do holiday club but only 6 days in the summer holidays due to lack of staff.

- One thing I have noticed repeatedly is that children with ALN are purposely denied support etc until they are compulsory school age (CSA). All children can attend school fulltime from the September before they are 5 in reception. I've rarely seen support for children set up to start reception if they will be under CSA. Children who are born in the summer are already disadvantaged if you look at the outcome stats let alone those with ALN. I have met only a handful of cases in the last 12 years when provision is in place for them to start reception when support needs are already well known, professionals already involved etc and they end up on a reduced timetable with full time support conveniently organised just before they reach CSA. Those children have the same right to attend the whole of reception fulltime like their peers.
- Childcare is nonexistent, my son has zero access to childcare, not even paid childcare because they aren't equipped to deal with his needs. I have been out of a solid job for 10 years because I can only work inside school hours and need school holidays off as he has no access to childcare. I'm very lucky his school understand he needs an outside curriculum learning style. So thankfully they teach him life skills...there need to be more options for this.
- Absolutely not! I trained as a nursery nurse in my early 20's and we did a lot of work on the various disabilities. This was far more than I learned as a trainee teacher on a Bed degree and I think the PGCE courses have even less detail – simply due to their intensity as a one year course – so no...For my daughter (profoundly deaf no speech) we needed above level 3 BSL support. Preschool nurseries that she went to were fantastic with her despite not being able to sign (we had to accept the limitation here and decided she's be incidentally educated through plan and learn how to interact to the best of her abilities. Primary deaf school was fantastic but the transitions between English and BSL were complex and the children had such varying language needs. Units were better in that the BSL support with the TA's was amazing - teachers not so good (how would they have the time for BSL fluency) and they have to provide for the range from hard of hearing to profound. Secondary school – based on our daughters high IQ we had to go for the oral approach – an extremely difficult decision she was placed in a small class with a signing one to one and did do exceptionally well but all due the Specialist deaf school academic approach and quality of teaching – teachers not so good (how would they have the time for BSL fluency) and the have to provide for the

range from hard of hearing to profound. Secondary school – based on our daughter IQ we had to go for the oral approach – an extremely difficult decision she was placed in a small class with a signing one to one and did do exceptionally well but all due to specialist deaf school academic approach and quality of teaching. Not – the primary deaf school was not in Wales - it was specialist deaf school in England – we upped and moved when our daughter was 2 to access this provision as trying to learn BSL from a mostly oral educated deaf community was not going to work for us – also can professionals acknowledge that SSE (Sign Supported English) is not a language – it’s a bridging/ translation tool between English/ BSL and while useful for explaining English structure, and useful for the hard of hearing – in my opinion as a parent of a profoundly Deaf child (also have a BSC in Deaf Studies), it should not be used on its own as a teaching tool for Deaf children.

- For me, I don't know, its lack of understanding of my son I find astounding despite me giving all the info to them, they still want to do it their way so he is compensating so hard. I see the ADHD – they refuse to so wont build evidence. He is half way between unit and mainstream at the moment. I'm grateful they understood he cant wake up and we can go in later, but im positive that comes from get him in at all costs, not from a place of true understanding. PDA needs to be recognized and understood in its own right.
- Another issue is there is no in-between ALN school and mainstream for those kids who are academically able but have high support needs and they themselves cannot cope with mainstream even with 1:1. My son and most other children I know his age are in this group. It's all well and good saying mainstream is the goal because these kids actually don't want that/ can't cope with that. High school seems to be when it really goes pear shaped. The noise, multiple classrooms multiple teachers, hug buildings etc. Most of these kids that can't cope with that are just contained in one class with no ambition at all for them. Unless you change all high schools to small primary school size, which isn't realistic in terms of cost or being able to staff that size with specialist subject tutors, mainstream will not work for these kids. Most end up coming out with poor, if any qualifications not because they weren't able but because LA's use inclusion to justify not meeting the needs of those kids. They get away with it because on stats they can say ALN and they are ignored because ALN is seen as equal to not able to learn. Two teachers have rescued my son from being excluded and fought his corner all the way

but the bottom line is had he been in a small school with a small class and specialist teaching, to the expected academic level rather than 'low ability' there is no reason he couldn't have done well. EG when home ed online, class of 10. He was due to sit maths gces a year early and predicted a B, even if he did nothing outside the class and English a C or D depending on if he worked. He chose to go back to school for GBSE and at best on a good day will get an E in maths and predicted an F/G for English. Forcing a child into an environment they can't cope with in the name of 'inclusion' isn't right. Everyone know I have had multiple run ins with schools over attitudes etc but realistically a teacher in high school teaches 100's of kids a week we can't expect them to remember every single need and have the capacity to accommodate that when roughly 20 % of the class have SEN. I couldn't remember every detail of my sons statement every day I certainly couldn't remember 100s let alone differentiate work for 100's it's just not realistic.

- Parent/carer 1 reply – *absolutely agree. I'm lucky in the sense my sons school has a half way scheme where it's not a unit but not mainstream and because of being academically able he has no interest in education because there is no reward quick enough, his dopamine isn't being addressed but the info about space and the stars all from tit ok 60 second bites he remembers and school just doesn't gear up for these kids.*
 - Parent/ carer 2 reply – *I totally agree with your comments. Sounds similar to my son who is now 18. We went the mainstream route for his education and it was a constant battle that took its toll on my health and left my son with amazing social skills but no real education. One teacher in secondary tried to differentiate his school work but they were not trained enough so it didn't really work. Secondary schools are not equipped or trained to teach children that fit in between special ed and mainstream so these children fall between the cracks.*
 - Parent/ carer 3 reply – *Agree – it is definitely harder at secondary age due to the size of schools/ classrooms and even despite the good intentions of many teachers, these children get left behind.*
- The answer is no. In our experience, parents of children with additional learning needs have to fight just to get the basic support they are legally entitled to and even with that fight and an educational lawyer involved its hard work. The schools rely on 'parental fatigue' to get away with as little as possible. I have full story I'd happily give you evidence on if you

need it. Please let me know how much information/ background you need.

- My son is in mainstream and is taken out of some lessons to do separate maths/ reading and joining his class in afternoons lessons. The funding given to schools is at the lowest pay level so schools cant attract the high level of teaching skills and knowledge required to support him. His school is lovely, very nurturing and kind and some of the teachers there are incredible but in order to teach him it needs specialist skills that don't exist at the level of funding. I noticed someone above commented about the middle ground being lacking. I feel like were in no man's land. Its arguable he doesn't need a whole 25 hours support what he really needs is 12-5 hours extremely good support.
- The other point that is really important here is that ALN training isn't compulsory for teachers nor is it compulsory for teachers in training. I didn't know this until my sons teacher told me one day that she might look at learning about autism! My heart dreopped out of my chest. I presumed that encouraging inclusive learning meant that they would have provided comprehensive compulsory training and onging training in ASD, ADHD and other ND's but they haven't. Looking back I can think of numerous teachers who haven't been trained. While school year where he was just existing there and not developing. I have positives too such as his involvement in current affairs, project work and all the new aspects of the curriculum such as citizenship. I could talk about this for hours.
 - *Parent carer reply and then the training is half a day, what gets me is the attitude of my training works on all children, so leave it with me and he will be fine..months later oh ok, you were right, so what do YOU think will help? 🙏. Or no we can't do that we have 30 other kids to consider 🙏 or yes yes we can do that, give that, then find out nothing is being done, they haven't even given that. Assessments that are out of date 6 months later that have taken 18months/2 years to complete 🙏*
- My daughter was put on the pathway route rather than mainstream GCSE subjects as she was placed in the provisional unit. The strong impression from the wording is that 'they can't cope with revision or exams'. This may apply to some but not all. It could potentially be an issue for my daughter as she has applied for the level 2 childcare course

at our local College. To be accepted onto the course she needs 2 GCSE's at grade C and English Language at grade D. She is only doing maths, English and Science as most of the other lessons are for a Btec qualification. We asked at the interview if BTEC was accepted and were told they weren't. She now has to achieve C in Maths but having completed her foundation exam early to then do intermediate maths the school hasn't supported her to get her ready for the exams. She needs 50% on both papers and is extremely stressed out as she doesn't feel ready and she doesn't want to do the level 1 college course as it would mean a total of 4 years in college. Being told she could re-sit it beforehand was not helpful either but I have resigned myself to the fact that even with an ALN education plan the general support is nonexistent. The complete ignorance about neurodivergent conditions is atrocious and that includes the provisional unit.

- Parent carer reply 1 : *Same here only allowed to sit core GCSE's, only because WG say they have to, then 'encouraged' to do vocational BTECs that sound ok as everyone knows what BTECs are, but later find out they aren't worth the paper they are written on they are just bits of BTECs they have no value in applying for college.*
- Author reply : *I just feel that once again they have failed her as her autism and ADHD were completely missed by primary school and I had to demand for her to be assessed. She finally had her full diagnosis last October but I have had to contact the school on numerous occasions to get issues sorted. We trust our children to be looked after by the education system and they fail them constantly, mostly due to their complete ignorance about EVERYTHING relating to the conditions. I am sick of 'behavioural issues' being punished when they are textbook symptoms that can't be helped.*
- Parent carer 2 reply : *So under the UNCRDP countries have to move towards an inclusive education system. It is also a sustainable development goal. All children able and thriving at their local school with all supports 😊 now we are a long way from this because it isn't even the aim yet! If Inclusive Education was realized then your children would be important to the one system and therefore matter to it...at the moment if you don't fit then you should be elsewhere...this is part of the issues everyone is facing...also its really important to talk to disabled activists..those with lived experience.*
- Author reply : *My daughter felt like she went backwards in the provisional unit as they were doing year 3 and 4 primary school work in year 7. It was an insult to her intelligence but she wasn't allowed to change to mainstream lessons because of her*

meltdowns. In fact that the reason she was having meltdowns in primary school was due to being undiagnosed and constantly triggered but their response was excluding her from school, behavior charts and time out in the blue room which was the sensory room. They dumped her in the provisional unit as they didn't know what to do with her. However, she wasn't getting the right support there either because she hadn't been diagnosed so they didn't have anything to support. The EP is an absolute legend and has been so supportive and helpful in getting as much support which she waived the 2 years to get her diagnosis. When she started year 9 he said put everything in place as if she has a statement and made a huge difference.

- Parent carer 2 reply : *if there wasn't an unit she would have mattered to mainstream.*
 - Author reply : *She said if she hadn't been in there she would have most likely been in the top maths class that the others she was in class in primary school have been in.*
- At 12 months old, I couldn't find a place in a private nursery for my son when I returned to work. All the nurseries turned us down, saying their insurance couldn't cover a disabled baby. Instead we had to employ a nanny. The care has been excellent and we have provided all the training, but it is the most expensive childcare option.
 - So when it came to music lessons at school my son didn't get the letter. I still managed to get him an audition. He was supported by someone who had never played a musical instrument – no idea!. He didn't get to learn an instrument at primary. At secondary school I asked for him to be in the orchestra (yes I did 🤪) I explained that the music system is discriminatory. They let him in. During lockdown I managed to source free African drumming online lessons, so that is now his instrument! He has thoroughly enjoyed being included in the orchestra. He LOVES music and loves being involved in the performances!

The impact of any lack of or limited access on a child or young person's mental health and well-being and educational outcomes.

- There is a lack of ALN places in our county. Mainstream schools struggle to meet the needs of these students and staff are not trained or have any understanding. Breakfast/after-school clubs can be a no go or struggle as again staff aren't trained and these can be very overstimulating environments.
- Our little one was excluded from after school club last week due to lack of staffing. We await the school's application for grant funding that they can advertise and recruit additional staff. So that will be a while to put in place. His needs have been known since Meithrin, now in year 2 and they've struggled all this time (Covid lockdowns notwithstanding).
- My son was systematically separated from mainstream at lunch and break times. His mainstream friends weren't allowed in the unit and the school felt it was better for him to be there for lunch citing the busyness and noise in the mainstream canteen. I kind of understand this but because he wasn't more fully included he struggled to maintain those friendships. This decision was made out of the best intentions but resulted in my son only being afforded disabled friends to eat lunch with. Inclusion is disabled and non-disabled together. My son already misses out on the ordinary conversations due to his communication difficulties which results in social isolation at any rate so schools need to give some attention to those long term repercussions of decisions to segregate based on disability. There needs to be people in school to encourage relationships between disabled and non-disabled learners, people who are experts on social inclusion. My son rarely gets invited to any ordinary social gatherings – possibly included once or twice annually. Most of the time I ensure that he is socially connected and outside of school I am able to train his PA's up to support him with this but these activities are planned organised activities generally. Intellectually disabled learners are generally segregated in school – it is essential that this practice is changed.

The barriers for schools and childcare providers in offering accessible provision

- There's a cultural challenge for schools to accept that they could and should include children with range of SEN and / or disabilities.

Particularly in Welsh medium primary schools that appear to have been left behind by local authorities.

- There is little understanding about learning disability. These children are written off quite early in school life and follow a very soft education. My son's mainstream education as a severely learning and physically disabled learner has depended on very dedicated, positive thinking staff. It isn't systematic. This is why we had to go to tribunal for him to go to a mainstream school. Under the UNCRDP which is written into the ALN act education should be delivered via Universal Design for Learning. Is this something new teachers are learning? Is it already in the training for staff?